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6 and 15

are not just numbers to us.

What is Dysautonomia?

It is pronounced
(Dis-auto-noh-mee-uh)

It is an umbrella term used to describe any disorder of the autonomic (involuntary) nervous system. These disorders usually involve abnormal symptoms in many organ systems such as cardiac, gastrointestinal, neurological, pulmonary, as well as others and can range from mild to disabling. Rare forms may be considered life threatening. Misdiagnoses can leave a person searching for answers for an average of six years. However, with proper awareness by our medical community, a diagnosis can occur in as short as fifteen minutes.

Perhaps you are receiving this newsletter on 6/15, or you may have made dinner reservations at a favorite restaurant for 6:15 p.m. Perhaps it is the exact time that you have set your alarm clock for tomorrow morning. But those numbers have an entirely different significance for The Dysautonomia Project. It involves our Mission Statement "to create awareness and raise funds for education of the medical community, healthcare providers and the general public about Dysautonomia, dysfunction of the Autonomic (Involuntary) Nervous System.

From 6 years to 15 minutes - bridging the gap between clinical research and physicians and patients at the local level.

A typical individual suffering with Dysautonomia waits an average of **6 years** to receive a diagnosis. Since most local physicians have about **15 minutes** to spend with each follow up patient our hope is that every community based physician will one day be able to recognize the common signs of dysautonomia and know how to direct the patient so they can receive proper care at the local level.



Save the Date!
OCTOBER 3, 2015

Second Annual VIP
Fundraising Event

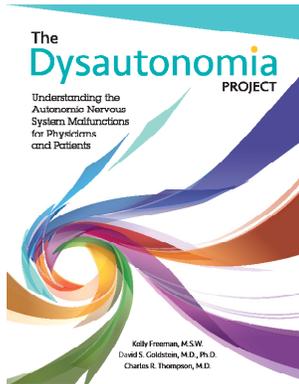
Mark your calendars now for this exciting night to remember. During the afternoon we will have patient and physician education about Dysautonomia and in the evening we will celebrate with local community leaders, friends and family.

This year's event will be held at duPont Publishing Headquarters, home of duPont Registry. It is the appropriate venue as we launch our new book! Join us for an exciting evening of fun, food, and enjoying the success of bringing

awareness to Dysautonomia.

For volunteer or sponsorship information, please contact us through the website at:

thedysautonomiaproject.org



The Dysautonomia Project Book

The Dysautonomia Project Book is an easy to read introduction to disorders of the autonomic (involuntary) nervous system (ANS) for both physicians and patients. The book is designed to:

- Facilitate a better dialogue between doctor and patient
- Be a helpful reference for physicians and others in the clinic
- Serve as a core text for the Grand Rounds CME Course

Designed for Better Dialogue

Core chapters are written with patient information on the left page and physician information on the right page of the book. This layout helps the physician and patient have a more meaningful dialogue. It also helps the patient to prepare well before diagnostic tests and follow up appointments. Academic chapters written by top researchers in ANS dysfunction and related conditions summarize key findings in recent research.

A Collaborative Effort

This book is a collaborative effort of many volunteer physicians and patients to speed the time to proper assessment and treatment of patients with dysautonomia at the community level.

The Dysautonomia Project Book is expected to be published in 2015*. The first edition will be available in paperback at a retail price of \$14.95. You can purchase the book before it is published to receive a discount.

Here are some simple ways you can show your support for The Dysautonomia Project:

- “Like” our Facebook page
- Wear Turquoise on June 15th and be ready to tell others about the Dysautonomia Project
- Save the Date for our annual Gala Fundraiser on October 3rd, 2015 at the duPont Publishing Headquarters
- Consider helping us with some of our administrative expenses with a donation of:
 - Forever STAMPS
 - Reams of Copy Paper
 - Office Supply Gift Cards
 - Amazon Gift Cards



PLEDGE OF COMMITMENT IN MEMORY OF CHRISTINA



You may recall reading an article in the Tampa Bay Times on March 8, 2015, about a beautiful, local, MIT freshman believed to have killed herself amid health difficulties. If you made it through the heartbreaking coverage, you learned that Christina E. Tournant suffered from postural orthostatic tachycardia syndrome, or POTS, a disorder of the autonomic nervous system under the Dysautonomia umbrella.

Christina E. Tournant It is because of this tragic outcome that the Board of Directors of The Dysautonomia Project has pledged to “carry the torch” to increase awareness of the many aspects of Dysautonomia. With unwavering determination, the Board will “continue the fight” to bridge the medical community with patients who suffer. Already, several events have taken place in Christina’s memory including a seminar titled “Depression & POTS” headed by Harvard Medical School trained Psychiatrist Doug Welpton, M.D.

If you are interested in donating in Christina’s memory, volunteering at an event to honor Christina, or want more information, please contact us through our Facebook page.

In 2014, The Dysautonomia Project:

- Educated more than 300 local community leaders about Dysautonomia including more than 25 local physicians and dentists.
- Recruited several renown academic and clinical physician experts to help as volunteer contributing authors and/or international advisory medical board members from many of the top autonomic research facilities in North America including David S. Goldstein, M.D., Ph.D, Randy Thompson, M.D. and Satish Raj, M.D.
- Created the promotional brochure for The Dysautonomia Project Book, due to be published in 2015.
- Launched The Dysautonomia Project website (www.TheDysautonomiaProject.org) with more than 1,200 visits to the site and over 200 visitors who “joined the project” in the first two months.
- Launched The Dysautonomia Project Facebook page with more 5.6k visitors and more than 550 “likes.” (<https://www.facebook.com/thedysautonomiaproject>)
- Recruited more than 250 volunteers both locally and in more than a dozen states across the country.
- Received nearly two dozen pre-orders for “The Dysautonomia Project Book” from several states and 3 countries including the United Kingdom, Spain and Australia.
- Lit the SunTrust Building Turquoise in honor of Dysautonomia Awareness Month.
- Received a Proclamation from City of Clearwater’s Mayor, George Cretekos, establishing the month of October as “Dysautonomia Awareness Month.”
- Created Awareness in the community through a ten minute Bay News 9 interview about Dysautonomia and our Project.
- Hosted our first VIP Kickoff Party, an educational fundraiser, for about 150 guests at Carlouel Yacht Club
- Raised approximately \$45k (net) to cover the publication costs of the book, development of the website with enough reserve to begin the first phase of physician education in the Tampa Bay region.

So Far In 2015:

- Pre-sold more than 30 books to members around the nation and world.
- Helped Diagnose 12 patients through local/out of town physicians using Patient Advocate Assessments.
- Educated several hundred teens & families about Dysautonomia during the funeral of Christina Tournant.
- Served as a connection between thousands in dysautonomia communities around the world and the family of Christina Tournant. Including presenting a hand made binder of more than 50 hand decorated letters of encouragement collected in 72 hours from around the world.
- Provided Depression & POTS Education to about 50 teens and families along with Doug Welpton, M.D.
- Published “Depression & POTS” article highlighting 5 Trends discovered in recent research including the need to use caution when prescribing SSRIs and/or NSRIs to patients with Dysautonomia.
- Reached 1100 “likes” to our facebook page with an average of 2 -3 posts each week.

Items Ahead in 2015

- CME Program Development
- School-Based Education
- Establish Monthly Patient Education Assessment Days
- Invited Patients to Join Case Study Volunteer Group
- Create a Database of interested/educated Local Medical/Dental Providers & follow up
- Connect regularly with International Medical Advisory Board members
- Plan for Dysautonomia Awareness Month Activities including confirming the lighting of the Suntrust Building and Plan for 2016 and another Bay News 9 Segment.
- Build Relationships with friends, associates in Tampa & St. Pete to connect physicians, community leaders & others with our October Event.

Karen Crown, Kelly Freeman and
Gus Bilirakis,
U.S. Representative





Meet the Board of Directors of The Dysautonomia Project: (Back row left to right) Ali Key, Melinda Ferm, Beth Pike, Nate Freeman, Kirk Blank, Molly duPont Schaffer, Polly Stannard, and Karen Crown, President (Front row left to right) Mary Elizabeth Welpton, Dr. Doug Welpton, Kelly Freeman, and Andrea Layman.

This is an amazing team of volunteer leaders in the community helping to spread the word. This board provides overall governance for the organization, including oversight, planning, fundraising and special events.

Spotlight on our Founders

Involved in The Dysautonomia Project are Tampa Bay area residents Karen Crown, and her daughter and son-in-law, Kelly and Nate Freeman. Kelly has been battling this for over three years. Her quest for answers has lead the family to form this federally approved non-profit organization. "Watching my daughter suffer by being undiagnosed, only to follow that with a misdiagnosis was extremely difficult as a parent. My background in the not-for-profit arena commands me to do all I can to alleviate this trauma for other families," stated Mrs. Crown, President of The Dysautonomia Project. Although the Project has launched in the Tampa Bay area, plans are in the works to replicate in other communities like ours. Joining Crown is son-in-law, Nate Freeman, who stated "Properly trained physicians can detect evidence of Dysautonomia in as little as 15 minutes. We are pledging our efforts to assist in moving the average from six years towards 15 minutes."

Please join this local family in support for those suffering from the myriad of complications surrounding Dysautonomia.



Patient Educational Session
Randy Thompson, M.D. seated



Local Medical Advisory Board

- Daniel Cabello, M.D.
- Ernesto Meyer, M.D.
- Laura Meyer, M.D.
- Ron Perrott, M.D.
- Paul Phillips, M.D.
- Frank Murphy (not pictured)
- Miguel Trevino, M.D.
- Doug Welpton, M.D.

Contact us at: The Dysautonomia Project | 13075 US Highway 19 N. | Clearwater, FL 33764

Or Call: Board of Directors

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